Introduced by Senator Liu

February 26, 2009

An act to add Section 4643.4 to Article 9 (commencing with Section 4699) to Chapter 6 of Division 4.5 of the Welfare and Institutions Code, relating to autism.

LEGISLATIVE COUNSEL'S DIGEST

SB 383, as amended, Liu. Autism Spectrum Disorders: screening. Existing law, the Lanterman Developmental Disabilities Services Act, requires the State Department of Developmental Services to contract with regional centers for the provision of various services and supports to persons with developmental disabilities, including Autism Spectrum Disorders (ASD).

Existing law, the California Early Start Intervention Services Act, commonly known as the Early Start program, provides various early intervention services for infants and toddlers who have disabilities or who are at risk of having disabilities to enhance their development and to minimize the potential for developmental delays.

This bill would require the State Department of Developmental Services to partner with at least one regional center to implement a 2-year Autism Spectrum Disorders Early Screening, Intervention, and Treatment Pilot Program in at least 3 key geographic areas. The pilot program would establish best practices for early screening, diagnosis, referral, and treatment for children with ASD.

The bill would require the department, no later than July 1, 2011, to report to the Legislature and the Governor on the pilot program. The bill would prohibit state general funds to be used to prepare the report

 $SB 383 \qquad \qquad -2-$

and to fund the pilot program in any fiscal year of the pilot program's operation. The department would be required to seek federal funding for the pilot program.

Under existing law, the State Department of Developmental Services contracts with private nonprofit entities, known as regional centers, to provide or purchase services and supports for persons with developmental disabilities, including Autism Spectrum Disorders (ASD). Existing law requires the department to develop and publish evaluation and diagnostic procedures for the diagnosis of autism spectrum disorders and to train regional center clinical staff in the utilization of those procedures.

This bill would require the department, not later than October 1, 2011, to provide recommendations for a system of universal screening for infants, and rescreening of children at 2 years of age, as specified, and would require the department to seek existing or new federal funding for this purpose.

Vote: majority. Appropriation: no. Fiscal committee: yes. State-mandated local program: no.

The people of the State of California do enact as follows:

- 1 SECTION 1. The Legislature finds and declares the following:
- 2 (a) The diagnosis of Autistic Disorder, Asperger's Disorder,
- 3 and Pervasive Developmental Disorder Not Otherwise Specified
- 4 all fall under the clinical umbrella term Autism Spectrum Disorders
- 5 (ASD).
- 6 (b) The number of children diagnosed with ASD has grown dramatically in recent years and is a serious public health crisis
- 8 that must be addressed. According to the federal Centers for
- 9 Disease Control and Prevention, ASD can now be diagnosed in
- 10 one of every 150 children and can occur in all ethnic, racial, and
- 11 socioeconomic groups.
- 12 (c) Autism Spectrum Disorders are complex neurological 13 developmental disorders with onset in early childhood that result 14 in substantial impairment in social interaction and communication 15 and in the presence of unusual behaviors and interests.
- 16 (d) Recent reports and studies have called attention to 17 significant gaps in programs and services for individuals with
- 18 ASD. Late identification and referral for intervention of young
- 19 children with ASD, insufficient preparation and reimbursement

-3- SB 383

of health care professionals, and inadequate collaboration between medical, home, and other systems of care that are important in comprehensive intervention are just a few challenges facing children with ASD and their families.

- (e) While it is now accepted and supported by research that early screening, diagnosis, and intervention, as well as timely access to services, can improve outcomes and help children with ASD function at higher levels, significant barriers exist to achieving these goals.
- SEC. 2. Article 9 (commencing with Section 4699) is added to Chapter 6 of Division 4.5 of the Welfare and Institutions Code, to read:

Article 9. The Autism Spectrum Disorders Early Screening, Intervention, and Treatment Pilot Program

- 4699. (a) As used in this article, "ASD" means Autism Spectrum Disorders.
- (b) The State Department of Developmental Services shall partner with one or more regional centers to implement a two-year pilot program in at least three key geographic areas around the state for the purpose of providing integrated and seamless services and systems of care for children with ASD who are deemed eligible for services and supports by regional centers.
 - (c) The goals of the pilot program include all of the following:
- (1) Identify solutions to improve early developmental screening protocols and coordination of referral, diagnostic, and treatment services for children with ASD between birth and five years of age, inclusive.
- (2) Develop a comprehensive model of best practices for early identification of children with ASD or other developmental delays and effective referral and coordinated followup care, focusing particularly on culturally, linguistically, and geographically diverse or underserved populations.
- 4699.1. (a) In order to achieve the goals of the pilot program, the department may consult with the following entities, as well as other interested stakeholders that the department deems necessary:
 - (1) The State Department of Public Health.
- (2) The State Department of Health Care Services.
- (3) The State Department of Mental Health.

SB 383 —4—

- 1 (4) The Department of Managed Health Care.
- 2 (5) University Centers for Excellence in Developmental 3 Disabilities.
- 4 (6) The State Council on Developmental Disabilities.
- 5 (7) The Association of Regional Center Agencies.
 - (8) The University of California.
- 7 (9) The American Academy of Pediatrics.
- 8 (10) The California Academy of Family Physicians.
 - (11) Local volunteers, including, but not limited to:
- 10 (A) Regional center staff.

- 11 (B) Health care professionals.
- *(C) Representatives from public and private health insurance* 13 *companies.*
 - (b) The pilot program shall do all of the following:
 - (1) Establish innovative, collaborative, integrated, and seamless methods, instruments, and systems of care between primary care providers and regional centers for the early identification and assessment of children with ASD from birth to five years of age, inclusive.
 - (2) Test the use of innovative methods to increase early screening for ASD, including, but not limited to, the use of parent-completed screening tools, more screening in community settings, and the use of Web-based tools and those that are compatible with electronic medical records.
 - (3) Determine how the use of telehealth and telemedicine strategies for professional development, outreach, and training for primary care physicians, residents in pediatrics and family practice, and medical students, as well as for clinical consultation, improves access to care in rural sites.
 - (4) Establish incentives for continuing medical education and other professional training and development and practice improvement to assist physician offices with implementation of universal early development screening, including, but not limited to, selecting, obtaining, and utilizing appropriate and validated screening tools and increasing knowledge of referral protocols and treatment options.
 - (c) In consultation with the State Department of Public Health and the State Department of Health Care Services, the department may test the following methods for the purpose of meeting the goals of the pilot program, as deemed appropriate by the department:

5 SB 383

(1) Implementation of the medical home model to improve coordination among physicians, families, regional centers, and other entities, as it relates to the evaluation screening, referral, and coordination of care and treatment for children with ASD.

- (2) Use of adequate payment and reimbursement strategies that will facilitate and provide incentives for routine screening and facilitate collaborative, coordinated, ongoing care to families within the context of a medical home.
- (d) The department and the advisory committee may partner with existing public, private, state, or national initiatives to share information and to avoid duplication of efforts and shall build upon the work and recommendations in recent reports and published models.
- (e) The Legislature recognizes that the regional center system serves individuals who are deemed eligible pursuant to subdivision (a) of Section 95014 of the Government Code and subdivisions (a) and (l) of Section 4512. Nothing in this article is intended to change existing eligibility requirements for receiving regional center services.
- 4699.3. (a) No later than July 1, 2011, the department shall provide to the Legislature and the Governor a report on the pilot program. The report shall make recommendations for legislative, regulatory, or fiscal initiatives that would further the goal of early identification and treatment of ASD and other developmental delays.
 - (b) The report shall specifically address all of the following:
- (1) The change in referral numbers and patterns from baseline historical trends after training in, and implementation of, screening, referral, and assessment protocols.
- (2) The planning and resource allocation required at the state and federal levels to build capacity in, and ensure access to, the regional center system and Early Start programs to prepare for the influx of autistic children and families that will result from routine screening.
- (3) Accessibility and diagnostic evaluation and intervention resources for children identified with ASD.
- (4) The fiscal impact on health care professionals and regional centers of increased screenings and referrals.

SB 383 -6-

(5) Changes in practice patterns for participating physicians, including residents establishing new practices, and other health care professionals.

- (6) Cost-effectiveness of routine early screening, referral, and intervention conducted in a coordinated fashion using the medical home model.
- (7) The impact on families in an environment of universal, widespread developmental screening, including the impact of false positives on parent-child interaction.
- (8) Other factors as the department and the advisory committee deem appropriate.
- (c) The preparation of the report shall be funded through federal, state, or private funds secured for the purposes of this section. State general funds shall not be used to prepare the report.
- 4699.4. State general funds shall not be used to fund the pilot program in any fiscal year of the pilot program's operation. The department shall seek federal funding to cover the pilot program.
- SECTION 1. Section 4643.4 is added to the Welfare and Institutions Code, to read:
- 4643.4. (a) The department shall provide recommendations for a system of universal screening for infants, and rescreening of children at two years of age, the age at which some conditions, including autism spectrum disorders, begin to manifest. These screenings shall be safe, secure, and available to every Californian who wants them.
- (b) The department shall seek existing and new federal funds to accomplish the goal descibed in subdivision (a), to the extent that this goal can be achieved without statutory changes.
- 29 (c) Not later than October 1, 2011, the department shall submit 30 the recommendations required pursuant to subdivision (a) to the 31 Legislature and the Governor.